IN THE UNITED STATES DISTRICT COURT FOR THE DISTRICT OF MAINE

BRENNA KANE, by her guardians and parents

Deanna and Kregg Kane,

and

DEANNA AND KREGG KANE, on their

own behalf,

: JURY TRIAL DEMANDED

Plaintiffs,

:

vs. : Civil Action No:

THE DEPARTMENT OF HEALTH AND HUMAN SERVICES FOR THE STATE OF MAINE, and

:

JOHN DOE, in his individual capacity,

:

Defendants. :

COMPLAINT

INTRODUCTION

1. This is a civil rights action for injunctive relief and damages under the Americans with Disabilities Act, 42 U.S.C. § 12101 *et seq.*, and the Rehabilitation Act of 1973, 29 U.S.C. § 794-797. Plaintiffs allege that the Defendants have violated those Acts by failing to accommodate Plaintiff Brenna Kane's need for community-based clinical services. Because of Defendants' violations, Brenna has been unnecessarily institutionalized for nearly a year, and Plaintiffs Deanna and Kregg Kane have become indebted for over a million dollars in medical bills for this unwanted and clinically unnecessary institutionalization.

JURISDICTION

- 2. The Court has jurisdiction under 28 U.S.C. § 1331 (federal question) and 28 U.S.C. § 1343 (3) and (4), this being an action filed under 42 U.S.C. §§ 12133 *et seq.*, and 29 U.S.C. § 794a(a)(2).
- 3. Venue is proper in this judicial district under 28 U.S.C. § 1391(b) because Plaintiffs reside in this judicial district and the events or omissions giving rise to these claims occurred in this judicial district.

PARTIES

- 4. Plaintiff Brenna Kane is a young woman with a variety of disabilities including:
 (i) Autism Spectrum Disorder; (ii) Disruptive, Impulse-Control, and Conduct Disorders; and (iii) Intermittent Explosive Disorder. Her permanent residence is her parents' home in Lewiston, Maine.
- 5. Brenna has been declared incompetent and her parents have been appointed her legal co-guardians.
- 6. Plaintiffs Deanna Kane and Kregg Kane are Brenna's parents and guardians and they reside in Lewiston, Maine.
- 7. Defendant Department of Health and Human Services ("DHHS") is a unit of government of the State of Maine. Its offices are located at 221 State Street, Augusta, Maine.
- 8. Defendant John Doe is the person or persons employed by the Department of Health and Human Services who failed to accommodate Brenna's need, and whom Plaintiffs intend subsequently to identify and add as defendant(s). He is sued in his individual capacity.

FACTUAL ALLEGATIONS

A. BACKGROUND ON APPLIED BEHAVIOR ANALYSIS.

- 9. Applied Behavioral Analysis (ABA) means the design, implementation, and evaluation of systematic instructional and environmental modifications to produce socially significant improvements in human behavior, including: (i) the empirical identification of functional relations between behavior and environmental factors, known as functional assessment and analysis; and (ii) interventions based on scientific research and the direct observation and measurement of behavior and environment.
- 10. Over the past 40 years an extensive body of literature has documented the successful use of ABA-based procedures to reduce problem behavior and increase appropriate skills for individuals with intellectual disabilities, autism, and related disorders.
- 11. Thousands of peer reviewed scientific journal articles demonstrate the efficacy of ABA.
- 12. Other than ABA, no scientifically validated treatment mechanism has had success in teaching people with disabilities like Brenna to reduce or eliminate problem behaviors.
- 13. As many as 50 percent of individuals with autism display problems with aggression or self-abuse.
- 14. The Surgeon General of the United States has stated, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior" in people with disabilities. (1999).

- 15. The Centers for Disease Control found that a "notable treatment approach for people with ... [disabilities] is called applied behavior analysis (ABA). ABA has become widely accepted among health care professionals and is used in many schools and treatment clinics...." The National Institute of Mental Health (NIMH) noted that ABA has become widely recognized as an effective treatment for individuals with autism. The National Institute of Child Health and Human Development stated that ABA is "a widely accepted approach that tracks a child's progress in improving his or her skills."
- 16. Professionals in Maine agree with these assessments: *See* Maine Administrators of Services for Children with Disabilities, "Report of the MADSEC Autism Task Force", at page 21: "Over the past 30 years, several thousand published research studies have documented the effectiveness of ABA...across a variety of populations, interventionists, settings, and behaviors."
- 17. Defendant DHHS has nevertheless refused to allow Brenna to be treated with ABA therapy in a community setting.

B. Brenna's History and DHHS' Denial of ABA.

- 18. Brenna began attending a specialized school for disabled children when she was five years old, known as the Margaret Murphy Center for Children.
- 19. While at Murphy, Brenna exhibited difficulties with aggression and self-abuse, particularly targeting her eye.
- 20. In early 2015, Brenna was engaging in 4.2 incidents of aggression or self-abuse per day.
- 21. With no effective treatment available due to DHHS's banishment of ABA, her problems became worse and worse.

- 22. Deana Kane specifically requested that the staff at Murphy take ABA-like actions to prevent Brenna from hurting herself, but was told this was not possible.
 - 23. By November of 2017, Brenna had blinded herself in one eye.
 - 24. By June 2018, Brenna's harmful behaviors had increased to 414 per day.
- 25. Because of Brenna's dangerous behaviors, Murphy referred her to the Neurobehavioral Unit of the Kennedy Krieger Institute in Baltimore, Maryland, and she was admitted there on June 27, 2018.
- 26. At the time of her admission, Brenna's maladaptive behaviors had grown dramatically worse in frequency and intensity. These included severe self-injurious behaviors (punching herself in face, eyes, and body; blinding herself in her left eye; banging her head on hard surfaces; biting herself; slamming her body into walls and floor; and pulling out her hair); aggression towards others (hair pulling, head butting, hitting, punching, kicking, biting); disruptive and destructive behaviors (screaming, breaking objects, knocking furniture over, throwing items); elopement (running from caregivers, leaving confined areas, such as school); spitting; and disrobing. These severe problem behaviors occurred in numerous outbursts daily.
- 27. The Kennedy Krieger Institute ("KKI") is one of the premier facilities in the world for the treatment of individuals like Brenna, with extreme behavior problems, and is a nationally recognized expert in the field of ABA
- 28. By November 1, 2018, and as a direct result of the ABA treatments provided to her by KKI professionals, Brenna's harmful behaviors were reduced to 0.85 behaviors per hour, and she was ready to be discharged into an appropriate setting in the community.

- 29. Beginning in August 2018, KKI and DHHS personnel discussed Brenna's return to a community-based clinical program in Maine.
- 30. During KKI's numerous contacts with DHHS, KKI repeatedly stressed Brenna's need for a community placement which would continue to utilize the ABA based behavior plan that had been so successful for Brenna at KKI. KKI offered to train the staff of any potential placement facility in the proper techniques in order to ensure that the placement was successful.
- 31. DHHS advised KKI and plaintiffs that they had the money to fund such a community placement and to purchase a house for Brenna.
- 32. Despite numerous requests by KKI and Brenna's parents, however, DHHS asserted that these ABA procedures were not permitted by state law and regulation, and DHHS refused to make an accommodation for Brenna's need for those techniques.
- 33. There is no clinical or scientific justification for DHHS's refusal to allow the use of her ABA-based treatment plan.
- 34. Defendants' actions in this case are such a substantial departure from accepted professional judgment, practice or standards as to demonstrate that no professional judgment at all was exercised.
- 35. As a direct and proximate result of DHHS's refusal to accommodate Brenna's need for a standard ABA treatment which has a documented history of success, Brenna has remained institutionalized at KKI for many months.
- 36. Between the date of her admission to KKI and September 6, 2018, Brenna's insurance company paid for her hospital bills at KKI.

- 37. On that date, Brenna's insurance company denied further coverage on the grounds that she no longer needed treatment at Kennedy Krieger.
- 38. As a result, plaintiffs Deanna and Kregg Kane have been responsible for the subsequent KKI bills, now totaling over a million dollars.
- 39. DHHS's conduct has significantly harmed third parties as well because there is a long waiting list at KKI of individuals like Brenna, with severe behavior problems, who cannot be admitted to KKI because Brenna is unnecessarily institutionalized there.

LEGAL CLAIMS

- 40. The Rehabilitation Act of 1973, 29 U.S.C. §§ 701-797, generally forbids discrimination on the basis of disability in (among other things) programs receiving federal financial assistance. *See* § 504, 29 U.S.C. § 794 ("No otherwise qualified individual with a disability * * * shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any [federal] program or activity * * *.").
- 41. The Americans with Disabilities Act ("ADA") "forbids discrimination against persons with disabilities in three major areas of public life: employment, which is covered by Title I of the statute; public services programs and activities, which are the subject of Title II; and public accommodations, which are covered by Title III." *Board of Trustees of Univ. of Alabama v. Garrett*, 531 U.S. 356, 372 (2001).
- 42. Title II of the ADA "simply extends the anti-discrimination prohibition embodied in section 504 of the Rehabilitation Act of 1973 to all actions of state and local governments." *Hatch v. Secretary of State of Maine*, 879 F. Supp. 147 (D. Me. 1995) (inner quotations and citations omitted).

- 43. Title II provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132.
- 44. Plaintiff Brenna has mental impairments that substantially limit one or more of her major life activities. She is therefore an individual with disabilities within the meaning of the ADA. *See* 42 U.S.C. § 12102(2); 28 C.F.R. § 35.104.
- 45. Plaintiff Brenna is also a "qualified individual with a disability" under Title II because she is an individual with a disability who, with reasonable modifications to DHHS policies, meets the essential eligibility requirements for participation in a DHHS placement program. *See* 42 U.S.C. § 12131(2); 28 C.F.R. § 35.104.
- 46. DHHS is a public entity under Title II. *See* 42 U.S.C. § 12131(1); 28 C.F.R. § 35.104.
- 47. The opening provisions of the ADA demonstrate Congress' intent to address the unnecessary institutionalization of persons with disabilities. Thus, Congress found that:
 - (2) historically, society has tended to isolate and segregate individuals with disabilities, and * * * such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;
 - (3) discrimination against individuals with disabilities persists in such critical areas as ** institutionalization; [and]
 - (5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, * * * failure to make modifications to existing facilities and practices * * * [and] segregation."

42 U.S.C. § 12101(a)(2), (3), (5).

- 48. Citing that language, the Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999), held that the ADA requires states to provide services to individuals with disabilities in the most integrated, non-institutional settings appropriate to their needs.
- 49. Defendant DHHS provides services to individuals with disabilities through MaineCare, which is Maine's Medicaid program, a state and federally funded program that provides medical and other related services to qualified individuals, including individuals with autism and related disabilities. Thus, title 34-b of Maine Revised Statutes, "Behavioral Service," states in § 5002.1 that it is the State's policy "to provide education, training and habilitative services to persons with intellectual disabilities or autism who need those services."
- 50. The Centers for Medicare and Medicaid Services (CMS) is the federal agency that oversees Medicaid. Services that are paid for through MaineCare must meet CMS requirements. In keeping with the ADA, CMS's rules for Medicaid-funded Home and Community-Based Services ("HCBS") are designed to assure that the services are provided in a community setting rather than an institutional setting.
- 51. The ADA on its face and as interpreted by the Supreme Court in *Olmstead*, as well as CMS's rules for Medicaid-funded Community-Based Services with which DHHS must comply to receive federal funding, require states to provide services to individuals with disabilities in the most integrated, non-institutional settings appropriate to their needs.
- 52. MaineCare provides community-based services as part of its program called "Home and Community Benefits for Members with Intellectual Disabilities or Autistic Disorder."

- 53. Section 5604 of Title 34-b, Maine Revised Statutes, provides that the rights of persons with autism "can be protected best under a system of services that operates according to the principles of normalization and full inclusion"; favoring "the development of community-based services that provide reasonable alternatives to institutionalization"; and providing services "that will maximize each person's potential to lead an independent and productive life."
- 54. With ABA therapy, Brenna is eligible for placement in a community placement setting, rather than the institutionalized setting of KKI. As evidenced by Brenna's experience at Murphy, however, where she received no ABA treatment and where her harmful behaviors increased to 414 times per day, and her experience at KKI, where ABA therapy reduced her harmful behaviors to 0.85 per hour, placing Brenna in a community placement without ABA therapy would not "maximize [Brenna's] potential to lead an independent and productive life" but instead would place her and those around her in grave danger of harm. As a result, without ABA therapy, Brenna will remain institutionalized.
- 55. The refusal by DHHS to permit the ABA treatment that Brenna needs has resulted in Brenna's continued institutionalization at KKI since the fall of 2018, in violation of the ADA.
- 56. DHHS has unlawfully "excluded [Brenna] from participation in [and] denied [her] the benefits of [MaineCare's community based] services" because of her disability, which requires ABA therapy, and has "subjected [her] to discrimination" by reason of her ABA-requiring disability. 42 U.S.C. § 12132.

- 57. Congress directed the Department of Justice to issue regulations implementing Title II of the ADA (*see* 42 U.S.C. § 12134(a)), and those regulations, found at 28 C.F.R. §§ 35.101 *et seq.*, "warrant respect." *Olmstead v. L.C.*, 527 U.S. 581, 597-98. (1999).
- 58. The Department of Justice Regulations provide that a public entity, "in providing any aid, benefit, or service, may not * * * [a]fford a qualified individual with a disability an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others * * * [or] [p]rovide a qualified individual with a disability with an aid, benefit, or service that is not as effective in affording equal opportunity to obtain the same result." 28 C.F.R. § 35.130(b)(1)(ii)-(iii).
- 59. DHHS has violated Title II and its implementing Regulations because it has afforded Brenna an opportunity to participate in a community placement *without* an effective ABA treatment program while it affords other disabled individuals who don't need ABA therapy an opportunity to participate in a community placement *with* a suitable treatment program.
- 60. DHHS has also violated Title II and its implementing regulations because it has insisting on providing Brenna a service community placement without ABA therapy "that is not as effective in affording equal opportunity to obtain" the benefits of that service, since without ABA therapy Brenna will be unable to live in a community placement.
- 61. The ADA Regulations further provide that a public entity must "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can

demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity." 28 C.F.R. § 35.130(b)(7)(i).

- 62. DHHS has failed to make reasonable modifications in its policies that are necessary to avoid discriminating against Brenna on the basis of her disability, and those modifications would not fundamentally alter the nature of MaineCare's community placement services.
- 63. DHHS takes the position that funding a community placement for Brenna that afforded her ABA therapy would violate Maine law and DHHS regulations.
- 64. The statute relied on by DHHS is Title 34 B: Chapter 5, Subchapter 4, Subsection 5605; 6. Personal property:

A person with an intellectual disability or autism is entitled to the possession and use of that persons own clothing, personal effects and money, except when temporary custody of clothing or personal effects by a provider is necessary to protect the person or others from imminent injury or unless this right has been restricted pursuant to rules adopted pursuant to section 5604.

- 65. That statute on its face does not prevent the use of the Token Economy ABA therapy in Brenna's case because the "temporary custody of [Brenna's] personal effects" while she earns access to them "is necessary to protect [Brenna] or others from imminent injury." Hence DHHS may not rely on that statute as a justification for refusing to fund ABA therapy for Brenna and thereby continuing her institutionalization.
- 66. The regulation relied on by DHHS is 14-197 C.M.R. Chapter 5, Appendix 5., which forbids "Requiring a Person to re-earn money or items that belong to them, or were previously earned" as well as "Removing or taking away money, tokens, points, activities or other Reinforcers that a Person has previously earned."

- 67. That regulation does not prevent the use of the Token Economy ABA therapy in Brenna's case because it, too, contains an exception for "Imminent Risk" to Brenna or others.
- 68. That regulation also does not prevent the use of the Token Economy ABA therapy in Brenna's case because all of the objects used in the Token Economy were purchased by her parents, and were never hers, and none of the prohibitions in the regulation are part of her treatment plan.
- 69. If the statute and/or the regulation does apply to Brenna and bars DHHS from funding ABA therapy necessary to permit her to be deinstitutionalized, it (they) violate the ADA and the Rehabilitation Act, and DHHS is required to make a reasonable accommodation to those provisions to avoid discriminating against Brenna and thereby violating those Acts.
- 70. Because they violate the ADA, the statute and regulation relied on by DHHS are invalid and unenforceable. *See Doe v. Rowe*, 156 F. Supp.2d 35 (D. Me. 2001) (invaliding a provision of the Maine Constitution that violated the ADA).
- 71. Prohibiting Maine from enforcing a discriminatory statute and regulation would not fundamentally alter the nature of MaineCare's community placement services within the meaning of the ADA.
- 72. DHHS has refused to fund Brenna's ABA-based treatment plan because of an arbitrary and unscientific dislike of ABA techniques. Expert testimony at trial will prove that there is no clinical or scientific justification for DHHS's refusal to fund Brenna's ABA-based treatment plan.

- 73. Defendants acted intentionally, willfully, with malice, and with reckless indifference to plaintiff Brenna's rights.
- 74. The refusal of Defendants to reasonably accommodate Brenna has resulted in her unnecessary institutionalization at KKI for over eight months, during which period plaintiffs' insurance company has not paid her hospitalization costs because institutionalization has not been necessary since November 1, 2018, with the result that Brenna's parents have incurred over \$1 million in medical bills that are directly attributable to Defendants violation of the ADA and the Rehabilitation Act.
- 75. Defendants violations of Brenna's rights caused substantial mental anguish and loss of enjoyment of life.

COUNT I: ADA – Failure to Accommodate

- 76. Paragraphs 1-75 are incorporated by reference.
- 77. Defendants' conduct violated the ADA's requirement that it provide qualified individuals with reasonable accommodations.

COUNT II: ADA – Disability Discrimination

- 78. Paragraphs 1-77 are incorporated by reference
- 79. Defendants' conduct violated the ADA's requirement that qualified individuals with disabilities be included in participation in and not denied the benefits of services, programs, or activities of a public entity.
- 80. Defendants' conduct violated the ADA's prohibition against discrimination by any services, programs, or activities of a public entity toward a qualified individual with a disability.

COUNT III: Section 504 of the Rehabilitation Act

- 81. Paragraphs 1-80 are incorporated by reference.
- 82. Plaintiff Brenna's mental impairments also make her a "qualified individual with a disability" under of Section 504 of the Rehabilitation Act, 29 U.S.C. § 794, and its implementing regulations. 45 C.F.R. §§ 84.3(j) and (k)(4).
- 83. DHHS is a recipient of federal financial assistance that operates programs or activities within the meaning of Section 504 of the Rehabilitation Act, 29 U.S.C. § 794, and its implementing regulations.
- 84. Defendants' conduct violated Section 504 of the Rehabilitation Act by subjecting plaintiff Brenna to discrimination solely by reason of her need for disability-related accommodations in violation of Section 504 of the Rehabilitation Act, 29 U.S.C. § 794, and its implementing regulations.

WHEREFORE, Plaintiffs pray that this Honorable Court:

- 1. Exercise jurisdiction over their claims;
- 2. Grant Plaintiffs preliminary and permanent injunctive relief requiring Defendants to provide Brenna the necessary accommodations needed for her to leave an institution and live safely in the community;
- 3. Award Plaintiffs compensatory damages for the injuries they have suffered;
- 4. Award Plaintiffs their attorneys' fees and costs under 42 U.S.C § 12205, and 29 U.S.C. § 794; and
- 5. Grant such other and further relief as may be appropriate.

Respectfully submitted,

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